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## Notice of Intended Regulatory Action (NOIRA) Agency Background Document

<b>Agency name</b>	Virginia Department of Health
<b>Virginia Administrative Code (VAC) citation</b>	12 VAC 5-190 (adoption of 12 VAC 5-191)
<b>Regulation title</b>	<i>State Plan for the Provision of Children's Specialty Services</i>
<b>Action title</b>	Repeal of 12 VAC 5-190-10 et seq. and replace with 12 VAC 5-191-10 et seq. using new title <i>State Plan for the Children with Special Health Care Needs Program</i>
<b>Document preparation date</b>	July 23, 2004

This information is required for executive review ([www.townhall.state.va.us/dpbpages/apaintro.htm#execreview](http://www.townhall.state.va.us/dpbpages/apaintro.htm#execreview)) and the Virginia Registrar of Regulations ([legis.state.va.us/codecomm/register/regindex.htm](http://legis.state.va.us/codecomm/register/regindex.htm)), pursuant to the Virginia Administrative Process Act ([www.townhall.state.va.us/dpbpages/dpb\\_apa.htm](http://www.townhall.state.va.us/dpbpages/dpb_apa.htm)), Executive Orders 21 (2002) and 58 (1999) ([www.governor.state.va.us/Press\\_Policy/Executive\\_Orders/EOHome.html](http://www.governor.state.va.us/Press_Policy/Executive_Orders/EOHome.html)), and the *Virginia Register Form, Style, and Procedure Manual* ([http://legis.state.va.us/codecomm/register/download/styl8\\_95.rtf](http://legis.state.va.us/codecomm/register/download/styl8_95.rtf)).

### Purpose

*Please describe the subject matter and intent of the planned regulatory action. Also include a brief explanation of the need for and the goals of the new or amended regulation.*

This regulatory action proposes repeal of the current State Plan for the Provision of Children's Specialty Services. The regulations will be replaced with the State Plan for the Children with Special Health Care Needs Program.

The current State Plan regulations do not adequately address the existing model for providing services to children with special health care needs. With the expansion of publicly financed health care coverage for children with special health care needs, the growth of managed care delivery systems, and a federal emphasis on developing systems of care that provide family-centered care coordination and services, the Virginia Department of Health discontinued the diagnosis-based, clinic direct service, Children's Specialty Services Program starting in 2000. Based upon results from a 1999 comprehensive needs assessment with families of children with special health care needs, changing federal emphasis, and examination of successful service delivery models, the state Children with Special Health Care Needs Program now contracts with

local entities to manage five regional Centers of Excellence known as Care Connection for Children Centers. The sixth Center is managed by the Children with Special Health Care Needs Program. Care Connection for Children Centers are affiliated with major hospitals and universities with the capacity to provide pediatric specialty care. These Centers provide care coordination, including family-to-family support and health insurance benefits counseling, to any resident of Virginia under age 21 with a chronic physical condition. In addition, the Children with Special Health Care Needs Program continues to administer a limited Pool of Funds to assist with payment of services for uninsured and underinsured children with special health care needs. The new regulations will amend the State Plan to meet the program's expanded and modified model of care and to address program requirements for access to the Pool of Funds, which is not an entitlement and subject to availability of funds.

VDH continues to operate Child Development Clinics across the state, another service under the Children with Special Health Care Needs Program. The Children with Special Health Care Needs Program also administers the state-mandated Bleeding Disorders (Hemophilia) Program. The replacement regulations will provide a State Plan for administration, eligibility, and scope of these two programs.

The anticipated result of the regulation is a State Plan that can be utilized to adapt to the changing needs of the population and transformations occurring within the health care system. The regulation will provide for utilization and management of appropriate guidance documents to assist with Virginia Department of Health's need to frequently evaluate and adapt its response to serving children with special health care needs.

### Legal basis

*Please identify the state and/or federal source of legal authority to promulgate this proposed regulation, including (1) the most relevant law and/or regulation, including Code of Virginia citation and General Assembly bill and chapter numbers, if applicable, and (2) promulgating entity, i.e., the agency, board, or person. Describe the legal authority and the extent to which the authority is mandatory or discretionary.*

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The State Plan for the Provision of Children's Specialty Services was first promulgated in 1987 and amended in 1990 under the authority of Sections 32.1-12 and 32.1-77 of the Code of Virginia. Section 32.1-12 of the Code authorizes the Board of Health to make, adopt, promulgate and enforce regulations. Section 32.1-77 authorizes the Board of Health to prepare, amend, and submit state plans for maternal and child health services and children's specialty services pursuant to Title V of the United States Social Security Act to the U.S. Secretary of Health and Human Services. Section 32.1-77 authorizes the State Health Commissioner to administer the plan and to receive and expend federal funds for the administration of the plan in accordance with applicable federal and state laws and regulations. While the authority to prepare and submit a State Plan exists in the Code of Virginia, no state or federal law mandates that this State Plan be developed or that services be provided.

Section 32.1-89 of the Code of Virginia mandates the Board of Health to establish a program for the care and treatment of persons suffering from hemophilia and other related bleeding diseases who cannot pay for the entire cost of their needed medical care. The Board of Health is given the

authority, but not mandated, to provide for certain services (e.g. payments for services, contracts to provide diagnosis and treatment, home health services, and program development).

The current State Plan was comprehensively reviewed in 1994 under Executive Order 15 and recommended for repeal. The recommendation to repeal was based on the availability of a suitable alternative (guidance documents, annual application for federal Title V funds, and program policy and procedure manuals) that could satisfy requirements of the Code of Virginia. Subsequent analysis by the Department of Planning and Budget and the Office of the Attorney General determined that parts of these programs affect the rights of persons and therefore regulations were, in fact, necessary.

## Substance

*Please detail any changes that will be proposed. For new regulations, include a summary of the proposed regulatory action. Where provisions of an existing regulation are being amended, explain how the existing regulation will be changed. Include the specific reasons why the agency has determined that the proposed regulatory action is essential to protect the health, safety, or welfare of citizens. Delineate any potential issues that may need to be addressed as the regulation is developed.*

The existing regulation, State Plan for the Provision of Children's Specialty Services, will be repealed and replaced by a new regulation. The new regulation will reflect the current models of delivering care for the Care Connection for Children Network, Child Development Clinics, and the Bleeding Disorders Program (Hemophilia). As specified under review conducted by the Office of the Attorney General, the regulation is necessary because these programs, most particularly access to the Pool of Funds for children with special health care needs, affect the rights of persons. A regulation will be developed which prescribes eligibility requirements and application to these programs. The regulation will establish the process for which eligibility guidelines and coverage are amended. In addition, the regulation will outline variance and appeals processes.

## Alternatives

*Please describe all viable alternatives to the proposed regulatory action that have been or will be considered to meet the essential purpose of the action.*

During the comprehensive review conducted under Executive Order 15 (94), alternatives to this regulation were considered. At that time, use of guidance documents, applicable federal directives, the annual plan submitted for receipt of federal Title V funds, and program policy and procedure guides were considered to be a viable alternative to the existence of regulations. The Office of the Attorney General determined in 2004, however, that a regulation is necessary to protect the rights of affected persons.

## Impact on family

*Assess the potential impact of the proposed regulatory action on the institution of the family and family stability.*

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This regulation should not have an effect on the authority and rights of parents in the education, nurturing, and supervision of their children. Parents have the choice whether to have their child participate in services offered by the children with special health care needs program. The only exception to voluntary participation would be if a child under state supervision were ordered by a judge to undergo evaluation at a Child Development Clinic.

The regulation may have an impact on economic self-sufficiency and disposable family income for those families who have a special health care needs child. The regulation will address eligibility for application to the Pool of Funds. The Children with Special Health Care Needs Pool of Funds provides a limited amount of money to assist Virginia's uninsured and underinsured children with special health care needs to receive care they otherwise could not afford. The Care Connection for Children (CCC) Program receives Title V funds from the federal Maternal and Child Health Block Grant and state general funds. The Pool of Funds is not mandated by any state or federal statute and is not an entitlement. The Pool of Funds is based on fund availability. The Pool of Funds may help increase disposable family income for certain families.

The regulation would not likely have any effect on marital commitment.

## Periodic review

*If this NOIRA is not the result of a periodic review of the regulation, please delete this entire section. If this NOIRA is the result of a periodic review, please (1) summarize all comments received during the public comment period following the publication of the Notice of Periodic Review, and (2) indicate whether the regulation meets the criteria set out in Executive Order 21, e.g., is necessary for the protection of public health, safety, and welfare, and is clearly written and easily understandable.*

The regulation was reviewed under Executive Order 15 (94). Notification of review and public comment period was published in the Virginia Register on January 23, 1995, and the period for comment ended on March 24, 1995. No public comments were received except from the Division of Children's Specialty Services Management Team. The Team commented that promulgating the State Plan as a regulation was not appropriate and an unnecessary burden in light of other viable alternatives.

The regulation moved through the Administrative Process Act procedures toward the goal of repeal. The Notice of Intended Regulatory Action to repeal was published in the Virginia Register on November 9, 1998 with public comment period through December 11, 1998. No comments were received at this time.

The Department of Planning and Budget raised concerns regarding enforceability and appeals during executive review for the repeal of this regulation.

After review by the Office of the Attorney General in 2004, it was determined that the regulation cannot be repealed in its entirety because certain programs in the State Plan for children with special health care needs affect the rights of persons.

Commenter	Comment	Agency response